

Workshop Report

Stake Holder Training Program

Thursday 29th March 2018

Organized by
State Nodal Agency Center(SNAC)
Satya Special School
Puducherry

In Association with HEPSN & CSSEIP
Pondicherry University
Puducherry

Funded by The National Trust
Ministry of Social Justice and Empowerment
Government of India



Stakeholder Training Program

29/3/2018

Summary

Satya Special School in association with Higher Education for Persons with Special Needs (HEPSN) cell and Centre for the Study of Social Exclusion and Policy (CSSEIP) conducted a one day training program for stakeholders in the field of persons with special needs to give them a fresh look at their profession and add an extra feather to their cap. The whole program was generously funded by The National Trust, Ministry of Social Justice and Empowerment, Government of India. The various stakeholders included anganwadi workers, government officials from the social welfare department, special educators from the various schools of Pondicherry which cater exclusively to persons with special needs, parents of PwDs, members of HEPSN and budding students and PHD scholars from Pondicherry University who chose to attend because of their camaraderie with persons with special needs who inspire them to become better people.

Training Module

- Legal Guardianship
- 4 disabilities of the National Trust including Learning Disabilities and availability of various support services to these persons
- Training on Activities of Daily Living (ADL)
- Self Advocacy
- Availability of technological service for PwD's
- Schemes and activities of the National Trust, Self Advocacy and Awareness among the general public and Government Officials

Background and Objective

This program was funded by the national trust to benefit the caregivers and parents of persons with special needs, who need to get all the help possible because raising a child in this day and age is difficult, but compounded with the challenges of raising a child with special needs the burden becomes too much to bear.

- Some people still think that children with learning disabilities are simply lazy and do not want to cooperate and are reprimanded for their behaviour over

which they have no control over, this pattern needs to end. The parents and caregivers need to know about the various learning disabilities to enhance their child rearing skills.

- Some teenagers with intellectual disabilities can name colours, shapes, letters and numbers but are unable to maintain basic sanitation and hygiene, are unable to eat without being fed, which is why a session on activities of daily living is organized. So parents and caregivers can teach children how to take care of themselves when their minds are plastic and can be moulded before it gets too late.
- Children with special needs also suffer when they don't have a legal guardian, some people don't have qualms of taking advantage of children with special needs because they can't express themselves and the perpetrator can get away scott free. If there is a legal guardian a child who cannot act on his own volition is protected by someone trustworthy.

Obtaining legal guardianship through the backlogged Indian court system is extremely difficult and can sometimes go on for months on end, which is why a new system has been developed using the internet which expedites the process. NGOs like orphanages can take legal guardianship of children to protect them from the avarice of relatives and those with untoward intentions.

- Many of the problems associated with disabilities could be overcome with the use of technology. So participants were made aware of them.

The organization and major themes of the workshop

The workshop created opportunity to various speakers to talk on different topics and to discuss some of the obstacles that the various stakeholders of PwDs face in their day to day life. Namely activities of daily living, the 4 disabilities covered by the national trust (autism, cerebral palsy, mental retardation and multiple disabilities), and about how to obtain legal guardianship using the internet.

Participants

The participants in this capacity building program were staff of special schools in and around Pondicherry, government staff from the social welfare department, parents of children with special needs, university students volunteering in HEPSN and anganwadi workers. In total 264 people were directly reached, sensitized and made aware of the various learning disabilities, national trust schemes, self advocacy and the new method of obtaining legal guardianship over the internet.

The staff of special schools who work directly with children with special needs need to be aware of the new developments in the field of disability management to be as effective as possible.

Inauguration



The program was inaugurated by the chief guest Mr.Thanigarasan - Registrar of Pondicherry University with special invitees Mr. Chidambaram Associate professor of Social Inclusion Exclusion Policy Pondicherry University, Dr.Malabika Deo Finance Officer of Pondicherry University and Ms Chitra Shah director of Satya Special School. They lit a lamp to signify an auspicious beginning and were honoured with a shawl a common custom in Tamil Nadu and the Union Territory of Pondicherry.

The welcome address was given by **Chitra Shah** director of Satya Special School who spoke on the new rights of persons with disability RPwD Act 2016, saying that it is wonderfully formulated and is one of the best legislation for persons with special needs



in the world. This Act must be implemented to better serve its beneficiaries.

Mr. Thanigarasan the Registrar of Pondicherry University spoke on the steps taken to facilitate the enrollment procedure and congratulated the timing of this program which happens to be when admissions are out for all the departments. The admission procedure does not require filling

out of forms and waiting in lines, but instead the new system is done through the internet. To apply one does not need a marksheet or a certificate, one can simply put “awaiting result” on the dropdown menu. The entire campus is differently abled friendly and the courteous security staff will help in any way possible. He then urged everyone present to not ask a person about his condition as it may negatively affect their self esteem but instead ask about their strengths.



Mr. Chidambaram associate professor of Social Inclusion Exclusion Policy and director of Higher Education for Persons with Special Needs (HEPSN) whose CV is the size of a binder despite having low vision spoke on the ongoing activities of HEPSN cell which is an enabling unit for differently abled pursuing higher education. Pondicherry

University has initiated measures that won the **National Role Model Institutions Award** of the **Ministry of Social Justice and Empowerment** in the year 2011. Pondicherry university provides complete free education for all the differently abled

students pursuing their higher education in the campus, complete waiver of hostel and mess fees, 65 of the 85 buildings in Pondicherry University have been made completely accessible for the differently abled and facilities are provided in the library for visually challenged students to access the resources through specialized software.

Now he would like to shift his attention to the Union Territory of Pondicherry to make all government buildings disabled friendly by lobbying in the local, state and national levels to reduce the burden on parents of persons with special needs.



Dr. Malabika Deo the finance officer spoke on how we need to be sensitive to the plight of persons with disabilities. She spoke about the 2007 movie *Taare Zameen Par* starring Aamir Khan where Ishaan an 8 year old child with dyslexia is constantly compared to his older brother who is an exemplary scholar and athlete. Ishaan excels in art but his parents fail to recognize his talent, which is why it

is upto Mr. Nikumbh the art teacher and special educator played by Aamir Khan to bring out what's best in him by using remedial techniques developed by dyslexia specialists.

She went on to speak on the fighter pilot in the Indian Air Force who flies the fighter jet in spite of not having legs and spoke on the the Indian contingent at the 2016 Rio paralympic games for the 100, 200 and 400 meter runs were faster than their able bodied counterparts in the Olympics. **“Persons with special needs are not disabled but rather *“Distinctively Abled”*”**.

Legal Guardianship

The 1st session was handled by Mr. Perumal Advocate by profession and runs the NGO called Adecorn Network, which provides counseling and legal aid to poor people and provides counseling to women.

Mr. Perumal first spoke about the importance of guardianship. He said that guardianship is a legal process whereby someone is given the authority by the court



to make decisions regarding major life decisions such as medical care, living arrangements, and sometimes financial management and act on behalf of a person who lacks the ability to comprehend and do those things for him/herself. The process is designed to protect an individual who cannot make decisions for himself/herself from being exploited, abused or neglected.

He then spoke about the benefits of registering a NGO under the national trust and spoke how difficult it would be to get guardianship of a child through the court as legal fees of lawyers are exorbitant.

He then went on to speak about the various schemes of the national trust. The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities.

2nd Session

The 2nd session was handled by Ms.Sudha Srinivasan. She spoke on the various mental disorders faced by children like dyslexia, dysgraphia, dyspraxia, dyscalculia. Children with these disorders understand only a portion of what is said to them and we as parents and teachers must be patient with them.



Dyslexia is to do with language. Abstract reasoning is a big problem for those who suffer from dyslexia.

Dyscalculia is to do with numbers. People with dyscalculia can't tell time and can't count money.

Dysgraphia is the inability to writejects and write with a lot of pressure. Something written on one page is visible through to the next five pages under. Dysgraphia affects their behaviour, they hide their notebooks and complain that the teacher is bad.



Dyspraxia is a developmental disorder of the brain in childhood causing difficulty in activities requiring coordination and movement.

Mrs Suddha then told a story about Nelson Mandela. Nelson Mandela was working for a rich white family in Johannesburg, South Africa. There he was ill treated and scolded for the smallest of infractions.

A balloon vendor came to his neighbourhood one day, Nelson Mandela asked the balloon vendor meekly if the black balloon can fly like all the other balloons. The balloon vendor said that it is not the colour that is important but rather how you conduct yourself.

She then conducted a demonstration on stage with two of the participants who had to draw a diagram of a flower simultaneously with the right and the left hands. This demonstration was to prove the problems faced by people with neurological conditions.



3rd Session

The 3rd session was handled by Mrs. Bora Sai Lakshmi the principal of Satya Special School. She spoke on the importance of activities of daily living. She berated that children recognize colours and numbers but are unable to remove their own underwear. Children can grow to be over 10 years old without knowing basic sanitation.



Activities of daily living includes eating/drinking, toileting, brushing, bathing, getting ready (dressing, grooming). A child must possess the various skills to perform household work, operate the telephone, handle money transactions and shopping. The people who need to be taught ADL include persons with physical disability, persons with intellectual disability, persons with autism and multiple

disabilities



4th Session

Mr Chidambaram associate professor of inclusion and exclusion policy and head of HEPSN spoke about his own personal experiences of advocacy and said that if one wants real change self advocacy is imperative. He said that when he used to work for rural people of Vellore the villagers always complained that the government is not doing enough, they expected maintenance grant for parents of persons with disability, and they thought that someone from Chennai the capital of Tamil Nadu can do something for them.

When a member of the legislative assembly who had the power to implement changes visited the village they would only ask for simple things like the bus to be on time and to stop at the bus stand when it does arrive. They did not talk about implementing real changes.

When the government officials heard about the activities that Mr. Chidambaram was conducting in his own time, they reprimanded him asking him why he was doing it without being asked. Mr. Chidambaram replied that these are activities that you should be doing, instead of scolding me you should instead promote me.

5th Session

The 5th session of the day was handled by Mr. Kupusamy associate professor of computer science in Pondicherry University. He spoke about the benefits of modern technology to aid persons with disability. He invited all those present to take a tour of the library.



He said that the current population of the world currently stands at 7.6 billion and out of them 1 billion people are persons with disability that is almost the population of the 2nd most populous nation India. The persons with disability must not be seen as a billion mouths to feed but rather 1 billion minds and bodies brimming with possibilities. If they are given the proper support they can be employable resource.



If one is unable to read because of it upon thousands of numbers.

Raja Raja Chola would not even dream of the sophisticated communication systems we have in place today.

“Persons with disability do not want a free pass they want to be able to enter the train”

Microsoft has a specialised autism recruiting division because they know that those with autism have a specific skill set not found in others,

When we talk to persons with disability one must never talk about their condition which may negatively affect their self esteem, but rather talk about their strengths.

Parents often send their autistic children for behaviour modification therapy after the age of fifteen. Psychological therapies must begin much earlier when the mind is pliable and open to new ideas.

There are bottom heavy fonts for people with dyslexia which makes it much easier for somebody with dyslexia to read.

Americans in San Francisco cannot make things suited for our needs, we must do it ourselves.

6th Session



The 7th session was handled by Arun Aloysius Mahesh, he is the administrator in vidya sudha, Sri Ramachandra Medical University, Chennai. He has more than 21 years of experience in the disability and rehabilitation field and has worked as a State Nodal Agency Center (SNAC) coordinator in Tamil Nadu for 11 years.

He first spoke on the national trust. The National Trust is a statutory body under the Ministry of Social Justice and Empowerment. It is set up under the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities Act, 1999 and has a corpus of 100 crore rupees. The national trust covers autism, cerebral palsy, mental retardation and multiple disabilities.

National Trust disabilities can be termed as Developmental Disabilities for which no definite medical cure is available but a lot can be achieved through Early Intervention, Training and Therapy but only if given appropriate training, people with above disabilities can work productively and contribute positively to their families & community

The National Trust offers registration to voluntary organizations, associations of persons with disabilities, and associations of parents of persons with disabilities so far 877 organizations have registered.

Under the National Trust Act, a Local Level Committee is required to be constituted in every district of the country for a period of three years with district magistrate or deputy commissioner, a representative of an organization registered with the National Trust and a person with disability

It is important for a person with disability to have a legal guardian. An adult with disability can have a legal guardian also. NT Act also provides mechanisms for monitoring and protecting the interests of the individuals and their properties. Legal Guardianship is not mandatory it is only need based. Legal Guardianship issue must align with concepts of Supported Decision Making, Legal Capacity and Rights of Persons with Disabilities in the light of UNCRPD.

The various schemes of the National Trust include Samarth Scheme which provide short term and long term residential services, Disha scheme a school readiness programs, Vikas scheme a daycare programs to help families of PWDs fulfil other responsibilities

In order to cover the persons with disability by providing government services they must be **Discoverable**. On

Feedback

The feedback of the program was largely positive, the staff from the various NGOs that deal with disability said that they now understood the importance of the national trust schemes and they would register their NGOs for national trust grants as soon as possible.

Some participant said that he did not know that this much useful information could be packed into just one day's training program.

Picture Gallery





